

**A STUDY TO ASSESS THE AWARENESS OF PARENTS ON  
LEUKEMIA AND THEIR STRESS WITH A LEUKEMIC  
CHILD UNDERGOING TREATMENT IN A SELECTED  
HOSPITAL AT COIMBATORE**

**M.Sc (NURSING) DEGREE EXAMINATION  
BRANCH II - CHILD HEALTH NURSING**

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**“A Study To Assess The Awareness Of Parents On Leukemia And Their  
Stress With A Leukemic Child Undergoing Treatment In A Selected  
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## **ABSTRACT**

A study to assess the Awareness of Parents on Leukemia and their Stress with a Leukemic Child undergoing treatment in a selected hospital at Coimbatore.

The aim of the study was, to assess the awareness of parents on leukemia and their level of stress regarding leukemic child undergoing treatment.

The study was conducted in a private hospital at Coimbatore. The conceptual frame work used in this study was Calista Roy's adaptation model. A descriptive survey approach was used for this study. The population of the study included all the parents aged 20 to 50 years attending the oncology out patient department of the selected hospital with their leukemic children for treatment at the time of the study. The sample consisted of 35 parents (35 fathers and 35 mothers) with leukemic child under treatment were selected by convenient nonrandom sampling technique.

Structural questionnaire and stress scale was used to assess the awareness on leukemia and stress scale among the parents. Data was analyzed by descriptive and inferential statistics.

Thirty two fathers (91.0%) and 31 mothers (89.0 %) had a high level of awareness regarding leukemia. Only three fathers (9.0%) and 4 mothers (11.0%) showed a moderate level of awareness with regard to leukemia. There was significant difference between the parents and level of awareness on leukemia. (t- test-1.21, df-68,  $p < 0.05$ ).

Majority of (68.57%) of the fathers and 37.14% of the mothers had moderate stress on leukemia where as 62.85% of mothers and 31.42% of fathers had severe stress on leukemia. There was no significant difference between the parents and level of stress on leukemia (t – test 0.64, df-68,  $p < 0.05$ ).

The study concludes that both fathers and mothers had awareness about the leukemia and they had severe stress regarding leukemic child undergoing treatment.

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I will triumph in the works of your hands”

- Psalm 92:4

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## TABLE OF CONTENTS

<b>CHAPTER</b>	<b>TITLE</b>	<b>PAGE NO</b>
<b>I</b>	<b>INTRODUCTION</b>	
	1. Background of the study	1
	2. Need for the study	9
	3. Statement of the problem	11
	4. Aim of the study	11
	5. Specific objectives	11
	6. Hypothesis	11
	7. Operational definition	11
	8. Assumption	12
	9. Delimitation	12
	10. Scope of the study	12
	11. Conceptual frame work	13
<b>II</b>	<b>REVIEW OF LITERATURE</b>	15
<b>III</b>	<b>METHODOLOGY</b>	
	1. Research design	25
	2. Setting of the study	25
	3. Population of the study	26
	4. Sampling size and sampling technique	26
	5. Sampling criteria	26
	6. Description of tool	27
	7. Scoring interpretation	28
	8. Construction of tool	29
	9. Content validity and Reliability	29
	10. Pilot study	30
	11. Data collection	30
	12. Plan for data analysis	31
<b>IV</b>	<b>ANALYSIS AND INTERPRETATION</b>	33
<b>V</b>	<b>DISCUSSION</b>	66
<b>VI</b>	<b>SUMMARY, CONCLUSION, IMPLICATION AND RECOMMENDATION</b>	70
	<b>BIBLIOGRAPHY AND REFERENCES</b>	75
	<b>APPENDICES</b>	79

## LIST OF TABLES

<b>S.No</b>	<b>TITLE</b>	<b>PAGE NO</b>
I	Frequency and percentage distribution of parents according to the demographic variables	35
II	Frequency and percentage distribution of children according to demographic variables	37
III	Frequency and percentage distribution of children based on illness and treatment	39
IV	Frequency and percentage distribution of parents according to overall awareness on leukemia	40
V	Mean awareness score, standard deviation of fathers and mothers with regard items related to meaning and reason on leukemia and significance.	41
VI	Mean awareness score and standard deviation of fathers and mothers with regard to item related to diagnosis and treatment on leukemia and significance	43
VII	Mean awareness score, and standard deviation of fathers and mothers in the three aspects of leukemia and level of significance.	45
VIII	Mean awareness score, and standard deviation of fathers and mothers in the overall awareness of leukemia and level of significance.	47
IX	Frequency and percentage distribution of parents according to level of stress in various areas	48
X	Frequency and percentage distribution of parents with regard to physical and psychological stress in three point scale	49
XI	Frequency and percentage distribution of fathers and mothers with regard to worry about child condition in three point scale.	51
XII	Frequency and percentage distribution of fathers and mothers with regard to family functioning in three point scale.	53

XIII	Mean stress score and standard deviation of fathers and mothers in three aspects of stress and level of significance	55
XIV	Mean stress score and standard deviation of fathers and mothers in over all stress and level of significance	57
XV	Frequency and percentage distribution of parents according to overall stress in three levels on leukemia	58
XVI	Association of demographic variables of mothers with their level of awareness on leukemia	59
XVII	Association of demographic variables of fathers with their level of stress on leukemia	60
XVIII	Association of demographic variables of data on children with their fathers level of stress	61
IXX	Association of demographic variables of mothers with their level of stress on leukemia	63
XX	Association of demographic variables of data on children with their mothers level of stress	64



## LIST OF FIGURES

S.NO.	TITLE	PAGE NO
1.	Conceptual framework	13
2.	Overall awareness of fathers and mothers regarding leukemia in percentage	40
3.	Mean score of parent's awareness on meaning, reason, signs and symptoms of leukemia in percentage.	41
4.	Mean score of parent awareness in diagnosis, treatment and care of the child on leukemia in percentage.	43
5.	Mean score of the fathers and mothers awareness in the three aspects of leukemia in percentage.	45
6	Mean score of the fathers and mothers in overall awareness on leukemia in percentage.	47
7	Mean score of the fathers and mothers in three aspects of stress on leukemia.	55
8.	Mean score of fathers and mothers in overall stress on leukemia in percentage.	57
9.	Overall stress of the fathers and mothers regarding leukemia in percentage.	58

# **INTRODUCTION**

## CHAPTER – I

### INTRODUCTION

#### BACKGROUND OF THE STUDY

Cancer in all stages of life, including childhood, have a common disease process cells grow out of control, develop abnormal sizes and shapes, ignore their typical boundaries inside the body, destroy their neighboring cells, and ultimately spread (or metastasize) to other organs and tissues. As cancer cells grow, they demand more and more of the body's nutrition. Cancer takes a child's strength, destroys the organs and bones, and weakens the body's defenses against other illness.

Cancer affects only about 14 of every 1,00,000 children in the United States each year. Among all the age group, the most common childhood cancers are leukemia, lymphoma and brain cancer. As children enter their teen age, there is also an increase in the incidence of osteosarcoma (bone cancer).

Cancer has become one of the main health problems in the present era. Cancer has become one of the ten leading causes of death in India. It is estimated that there are nearly 12-15 million cases at any given point of time. Over the 7 lakhs new cases of cancer and three lakhs deaths occur annually due to cancer. **(WHO 2002, NCCP)**

The burden of cancer in India is on rise and the recent cancer registry report still shows the same striking findings as shown in the first cancer registry report that is 75 – 80%. **(NCRP, 2006)**

Cancer, by definition, is a disease of the genes. A gene is a small part of Deoxyribonucleic Acid (DNA), which is the master molecule of the cell. Genes make "proteins," which are the ultimate workhorses of the cells. These proteins that allow our bodies to carry out all the many processes those permit us to breathe, think, move, etc.

Cancer is not a new disease. It can be found on Egyptian papyrus dating back to roughly 1600BC. The Egyptians blamed the disease on the Gods and treated it with a cauterizing tool they called “the fire drill”. Apparently the drill did not work, as the writing on the papyrus says, “There is no treatment”.

The Greek physician **Hippocrates** is believed to be the first person to use the word “carcinos”, which describes the crab-like way that both the ulcer-forming and non ulcer forming tumors spread. Over time, the word shortened to cancer.

When the first autopsy was performed by an Italian anatomist **Giovanni Morgagni** in 1761, the foundation was laid for the scientific study of cancer, also known as oncology.

The 18<sup>th</sup> century **John Hunter** was one of the first people to suggest operating a tumor. Unfortunately for his patients, anesthesia was not developed until a century later. Not surprisingly, surgery began to flourish once anesthesia was introduced.

Leukemia was not officially diagnosed until 1845, when **John Hughes Bennett** diagnosed it in Edinburgh (**Greaves, 2000**). Other European physicians in the 19th century observed that their patients had abnormal high levels of “white blood”. The term leukemia that is used now comes from the Greek word “lekose” and hemia”, also meaning “white blood”. In 1970 it was first confirmed that some patients could be cured of leukemia, and by the 1980s and 1990s the cure rates for leukemia were around 70%.

Leukemia is a cancer of the tissues that produces blood cells, resulting in abnormal blood cells. Leukemia appears to be related to damage to chromosomes or genes. The damage disrupts the process by which blood cells achieve their final and functional form. (**NCI - 2000**)

Leukemia is the most common kind of cancer in children. Leukemia also causes more deaths than any other form of cancer in children. Fortunately, improved treatment methods have greatly reduced deaths from leukemia. Leukemia rates are higher for children of white than the others. There are several

forms of leukemia, two of which are particularly important in children. These are usually known as Acute Lymphoblastic Leukemia (ALL) and acute Myelogenous Leukemia (AML).

Prevalence rate of leukemia in most population in the world ranges from 75 to 150 million children per year. However the reported age of the standardized incidence rate for India ranges from 38 to 124 million children per year. In India the highest incidence reported from Chennai and lowest from rural Ahmadabad. The incidence in urban areas (like Bangalore, Bhopal, Chennai, Delhi, Mumbai) is generally higher than from rural areas (like Barshi and Ahmadabad district) and more comparable with the average world incidence. Leukemia is the common childhood cancer in India with relative proportion varying between 25 to 40%, 60 to 85% of all leukemia's. **(Arora R S)**

Within a population of 882 million, six thousand children will develop acute lymphoblastic leukemia each year in India. These children come from three socio-economic backgrounds: Profile I (70%) - being extremely poor who cannot afford any treatment unless it is provided free; Profile II (25%)- from the middle class, and Profile III (5%)- who can afford to have the best possible treatment. Since state resources are limited, the paediatric oncologist in India has to decide on the appropriate treatment protocol for the individual child in each of these profiles. **(Mammen Chandy M D)**

Acute lymphoblastic leukemia (ALL) is the most common form in children and represents 78% of cases of leukemia. From 1991 to 1994, the incidence rate was 59 cases per million of under five children. ALL reaches its greatest frequency in children between 2 and 6, with a peak of more than 80 cases per million children per year at ages 3 to 4, rates then decline to age 20. **(Smith M A)**

ALL increased about 1% per year between 1977 and 1995, though some of the change may result from changes in the groups that are tracked for cancer. However, many scientists believe that this change represents a genuine increase in the frequency of the disease that could be caused by environmental factors. Acute non-lymphocytic leukemia is the second most common form of

leukemia in children and represents 19% of cases. It is also called acute myelogenous leukemia (AML). It is the form of leukemia most commonly diagnosed in children less than one year old. Rates are higher at ages 1 to 3 and in late adolescence. Unlike ALL, the rates for AML do not appear to have increased since 1975. **(Smith M A)**

Overall cancer in childhood is more common in males than females. People can get leukemia at any age. Some risk factors for AML are, certain chemotherapies used for lymphoma or other types of cancer, down syndrome and some other genetic diseases, chronic exposure to benzene (such as in the workplace) that exceeds federally approved safety limits, radiation therapy used to treat other types of cancer.

Exposure to high doses of radiation therapy is also a risk factor for ALL and CML. Other possible risk factors for the four types of leukemia (acute lymphocytic leukemia, acute myelogenous leukemia, chronic lymphocytic leukemia, and chronic myelogenous leukemia) are continually under study.

Both prenatal and postnatal exposure to **ionizing radiation** (particularly X-rays can cause leukemia in children). Pre-natal exposure to X-rays has been greatly reduced with the adoption of ultrasound for screening in pregnant women.

**Ionizing radiation** is considered as a "known" cause of childhood leukemia. People who survived the detonation of atomic bombs at Hiroshima and Nagasaki found that the risk of leukemia was higher for those exposed to radiation. The risk is also higher for those exposed at an earlier age. Radiation from nuclear power plants is a known cause for both kinds of leukemia. **(Schmitz – Feuerhake I)**

A recent study found that exposure to **X-rays** after birth also increased the risk of leukemia. Infants receiving diagnostic X-rays had 60% more leukemia than other children.

Radon is a naturally occurring **radioactive gas** that gets into homes from materials underneath houses, such as soil or rocks, or from water piped into the

houses. Two studies have investigated whether radon exposure is related to ALL but have not found any relationship. Both of these studies were limited in the conclusions that they could draw because participation rates were low. One earlier study reported that an association between levels of radon in geographic areas and increased risk of childhood leukemia. **(Gilman E A)**

Several studies link **pesticide** exposure by both parents and children to leukemia. The pattern of disease suggests that some damage to chromosomes may occur before the child is born. **(Sandler D P)**

Children born to parents employed in certain occupations that have chemical exposures are more likely to have leukemia. **Chemicals**, specifically including benzene, have been shown to cause leukemia in adults. **(Ross J A)**

**National Cancer Institute study (1987)** reported that the risk of childhood leukemia increased nearly four times when **pesticides** were used within the house at least once per week. The risk increased more than six times when garden pesticides were used at least once per month.

In 1998 epidemiological review concluded that the evidence for an association between childhood leukemia and paternal exposure to solvents is "quite strong." Chemicals where risks are elevated include **solvents** in general, chlorinated solvents, benzene, carbon tetrachloride, and trichloroethylene (TCE). **(Colt J S, Blair)**

These studies tend to look at the occupation of fathers more often than those of mothers, despite the fact that exposures of mothers are likely to be at least as important. For occupations of the mothers, the review concluded that the most significant were employment in personal services industries, in metal processing, and in textiles. All three categories had significantly elevated risks. For occupations of fathers, employment in **painting** led to increased risk of leukemia in a child. **(Brondum J)**

Some of the studies reported that exposure to **electric and magnetic fields** (EMFs) are associated with increased risk of leukemia. Evidence about whether

Electric and Magnetic Fields (EMFs) contribute to leukemia in children is contradictory, with some studies finding an effect and others not finding an effect. However, there are many ways to measure these fields, and the various approaches do not correlate in all cases. Some of the contradictory results could be due to differences in methods of measuring the EMFs. Also, as is true with other possible causes, there may be a specific time period when children are most susceptible. Studies do not necessarily identify the relevant time period. **(Kleinerman R A)**

More positive results are found when EMFs are measured according to "wire codes," which are classifications based on how wiring is configured than when EMFs are measured directly. **(Miller M A)**

Several studies have found that exposure to EMFs increases risk of leukemia in children. One study found that children living near high voltage power installations were more likely to be found to have leukemia than other children. However, other studies have failed to find any link. **(Kleinerman)**

Some signs or symptoms of leukemia are similar to other more common and less severe illnesses. Specific blood tests and bone marrow tests are needed to make a diagnosis. Signs and symptoms vary based on the type of leukemia.

For acute leukemia, they include, tiredness or no energy, shortness of breath during physical activity, pale skin, mild fever or night sweats, slow healing of cuts and excess bleeding, black-and-blue marks (bruises) for no clear reason, pinhead-size red spots under the skin, aches in bones or joints (for example, knees, hips or shoulders), low white cell counts, especially monocytes or neutrophils, not contagious.

Child with CLL or CML may not have any symptoms. Later, enlarged lymph nodes in the neck, armpit or groin, feel tired or short of breath (from anemia) or have frequent infections, CLL is more severe. In these cases, a blood test may show an increase in the lymphocyte count, night sweats and weight loss, enlarged spleen (leading to a "dragging" feeling on the upper left side of the belly).



A complete blood count (CBC) is used to diagnose leukemia. This blood test may show high levels of white cells and show leukemic cells in the blood. Sometimes, platelet counts and red cell counts are low. Bone marrow tests (aspiration and biopsy) are often done to confirm the diagnosis and to look for chromosome abnormalities. These tests identify the leukemia cell-type.

The ways in which patients are affected and how children are treated differently for each type of leukemia. Blood tests and bone marrow tests are used to identify AML, ALL, CML or CLL subtypes.

The aim of leukemia treatment is to bring about a complete remission. Today more and more leukemia patients are in complete remission at least five years after treatment.

Child with an acute leukemia needs to start treatment right away. Usually, they begin induction therapy with chemotherapy in the hospital. More inpatient treatment is usually needed even after a patient is in remission; this is called consolidation therapy or post induction therapy. This part of treatment may include chemotherapy with or without allogeneic stem cell transplantation (sometimes called "Bone marrow transplantation").

Allogeneic stem cell transplantation is the only treatment that can cure CML at this time. This treatment is most successful in younger patients. Allogeneic transplantation can be a high-risk procedure. Studies are under way to see whether CML patients have better long term outcomes with drug therapy or with transplantation.

Some CLL patients do not need treatment for long periods of time after diagnosis. Patients who need treatment may receive chemotherapy or monoclonal antibody therapy alone or in combination. Allogeneic stem cell transplantation is a treatment option for certain patients.

AML, ALL, CML and CLL children who are in remission need to see their doctors regularly for examinations and blood tests. Bone marrow tests may be

needed from time to time. The doctor may recommend longer periods of time between follow-up visits if a child continues to be disease free.

## **IMPACT ON FAMILY AND COPING**

Families face uncertainty when they are told that their child has leukemia or lymphoma. Children with leukemia or lymphoma may face long period of treatment. However most can expect to have full and productive lives. Many childhood cancer survivors return to school, attend college, enter the workforce, marry, and become parent. Still each family living with a childhood cancer diagnosis is thrown to in an unfamiliar world.

Child with cancer diagnosis may produce a jumble of reactions for the parents including shock, confirm, denial, fear, anxiety, anger, grief and sadness. The parent's sense of security and their religious or spiritual beliefs may be shaken. Many parents experience this mix of feelings throughout their child illness. It is common for family members including parents to react differently from one another to the initial diagnosis. Each person is an individual with her own way of expressing emotion and there is no right way to feel or react. Parent often balance each other, with one being the worries and the other one remaining calm. Given the intensity of the experience, the emotion it evokes and the member of important decision to be made.

The logistics of day-to-day life require that thing be constantly worked out. This was perceived by the families to be more demanding of their energy and resources than typical family life. Five basic processes were found to be associated with working things out (Balancing, managing, adapting, tolerating and maintaining the family image). In addition to these family-level processes, several individual-level concepts were described in this research, all related to keeping perspective within the family unit for example parental monitoring and managing which includes the special skills needed to interact with the health care system. Affected and well children also have unique, additional work to do. This research is broadly applicable to the understanding of families in health care particularly

when a child has a chronic condition. Nursing and other health care interventions, programs, and policy could be designed that better address family care. The researchers also give direction for further basic research as well as intervention / outcome studies.

## **NEED FOR THE STUDY**

“Children are the wealth of tomorrow... take care of them if you wish to have a strong India, ever ready to meet various challenges”.

Children are more susceptible to diseases for a number of reasons. The major reason is that they have had limited exposure to pathogenic organisms and therefore havenot yet built the immunologic defense required to tend off certain diseases.

The incidence of childhood leukemia in modern times may be life style related. In developed countries families are usually smaller and hygiene has improved. Infants are no longer exposed to infections at an early age (**Greaves 2000**).

Our immune systems have evolved to respond to infections shortly after birth, usually through the mothers antibodies during the breast feeding. The immune system of children exposed at later ages, without having confronted microbes at an earlier age, may not respond as well. These children may have increased risk of developing leukemia.

The incidence of leukemia is higher among the more industrialized nations, because these people are living in an environment that is least like environment humans evolved to fit.

Leukemic children can never be isolated; it is a life threatening event, which the child and parents react differently to illness. Parents behavior and emotional reaction depends on the nature of the child illness and parents attitudes towards it.

When the parents clearly understand about the child condition, that is the meaning, causes and the management of leukemia, it will help them to provide effective care to their children.

In earlier days the leukemic child was not brought to the hospital due to lack of awareness. But today, the situation has been changed due to modernization and advanced treatment.

Leukemia is an important health problem in growing children, so now a day's giving more attention to that problem; literature highlights the prevalence of the problem in the worldwide. The increasing incidence of leukemia due to genetic mutation, environment, and diet.

In hospital stay the health care provider mainly focuses on the sick child and after the discharge also the team mainly concentrates on child's signs and symptoms. But they are not concentrating on the care giver that is the parents, developing an understanding of the impact that childhood cancer has on the lives of children and their families is essential to be able to provide comprehensive and sensitive care to them.

Few would argue that parents experience intense and extreme distress when their children are being treated for cancer. Parents are present during upsetting procedures or treatments and struggle with their own anxiety this cause disruption to their families. This psychological trauma that parents experience may lead to subsequent post traumatic stress. As cancer in their child they elicit feelings of hopeless with intrusive memories, physiological arousal, and isolated from the society.

Also the investigator on reviewing the literature has found that only few studies have been done regarding the coping of the parents and the child, more studies that are focused on health related quality of life of the leukemic child. The investigator has felt that the study would help the nursing practitioner to understand the parent's awareness and stress level and provide necessary information for promoting the emotional well being.

### **Statement of the problem**

A Study to assess the Awareness of Parents on Leukemia and their stress with a Leukemic Child undergoing Treatment in a Selected Hospital at Coimbatore.

### **Aim of the study**

The aim of the study was, to assess the awareness of parents on leukemia and their level of stress regarding leukemic child undergoing treatment.

### **Specific objectives**

- ❖ To assess the level of awareness of fathers and mothers with regard to leukemia.
- ❖ To assess the level of stress of fathers and mothers having children with leukemia.
- ❖ To find out association between the level of awareness of parents about leukemia and their demographic variables.
- ❖ To find out association between the level of stress of parents with a leukemic child and their demographic variables.

### **Hypothesis**

**H<sub>01</sub>** . There will be no significant difference between the awareness of fathers and mothers having leukemic child.

**H<sub>02</sub>** . There will be no significant difference between level of stress of fathers and mothers having leukemic child.

### **Operational definitions**

**Awareness:** Is the information or ideas which a person holds with regard to something. In this study it is the information or idea held by the fathers and mothers with regard to leukemia and its detail, which is self reported on questioning.

**Leukemia:** Is a type of cancer that starts in the soft, inner part of the bones (**bone marrow**) and often moves quickly into the blood. It spreads to other parts of the body such as the lymph nodes; it will disturb the functions of blood forming organ and leads to death.

**Stress:** Is the difficulty, problem, uneasiness or tension, experienced by someone due to a situation, events or happening. Here, the difficulties or problem, tension experienced by parents as a result of having a leukemic child is expressed and measured on a scale.

### **Assumption**

1. Leukemia is a worldwide problem.
2. Leukemia can causes physical, psychological and family functional disturbances
3. The views of fathers and mothers and their approach to leukemic children will have variation.
4. Awareness of parents on leukemia and its management may influence their support to the leukemic child.

### **Delimitation**

The study is delimited to,

1. the parents attend the leukemic clinics located in Coimbatore
2. the parents aged from 20 years to 50 years.
3. the parents having children with leukemia in the age group 5 to 15 years.

### **Scope of study**

Through this study, the researcher can determine the awareness and stress level of parents on leukemic child who is undergoing treatment. By assessing the awareness on leukemia in different aspect; the areas of less awareness can be

identified. It will highlight the level of stress experienced by the fathers and mothers in coping with a leukemic child.

The perception of parents regarding leukemic child, it helps to give the effective care to the leukemic child and also reduces the stress level.

All these findings will help the health care provider to take appropriate action to create awareness among parents on leukemia and their stress level and conducts awareness programs to parents and public in order to reduce their stress level. The findings of the study will be useful to understand the nature of problem and also it will be useful to the leukemic children through their parents.

## **CONCEPTUAL FRAMEWORK**

Conceptual framework refers to interrelated concepts or abstractions that are assembled together in some rational scheme by virtue of their relevance to a common theme (**Polit and Hunger 1999**).

Theoretical model for this study was derived from **Callista Roy's Adaptation Theory (1996)**. Roy employs a feedback cycle of input, throughput and output. Input is identified as stimuli, which can be from the environment or from within a person. Stimuli are classified as focal, contextual, or residual (non specific such as cultural beliefs or attitudes about illness). Input also includes a person's adaptation level (the range of stimuli to which a person can adapt easily).

Throughput makes use of a person's processes and effectors. "Processes" refers to the coping mechanisms that a person uses as an adaptive system. In processes consists of interaction within the parents, collection of data, and clarification of data and assess the parents awareness on leukemia. "Effectors" refers to the physiological function, self-concept, and role function involved in adaptation. It consists of assess the level of stress among the parents, psychological support and counseling to parents improves self concept of the parents.

In the adaptive system, the term "system" is defined as self parts connected to function as whole for some purpose and it does so by virtue of the

interdependence of its parts this has two major internal control processes called “regulator” and “cognator”.

Regulator sub - system consists of input, internal processes and output. Input stimuli can come from the environment. Internal processes including chemical, neural and endocrine transmit the stimuli, causing output, a physiological response.

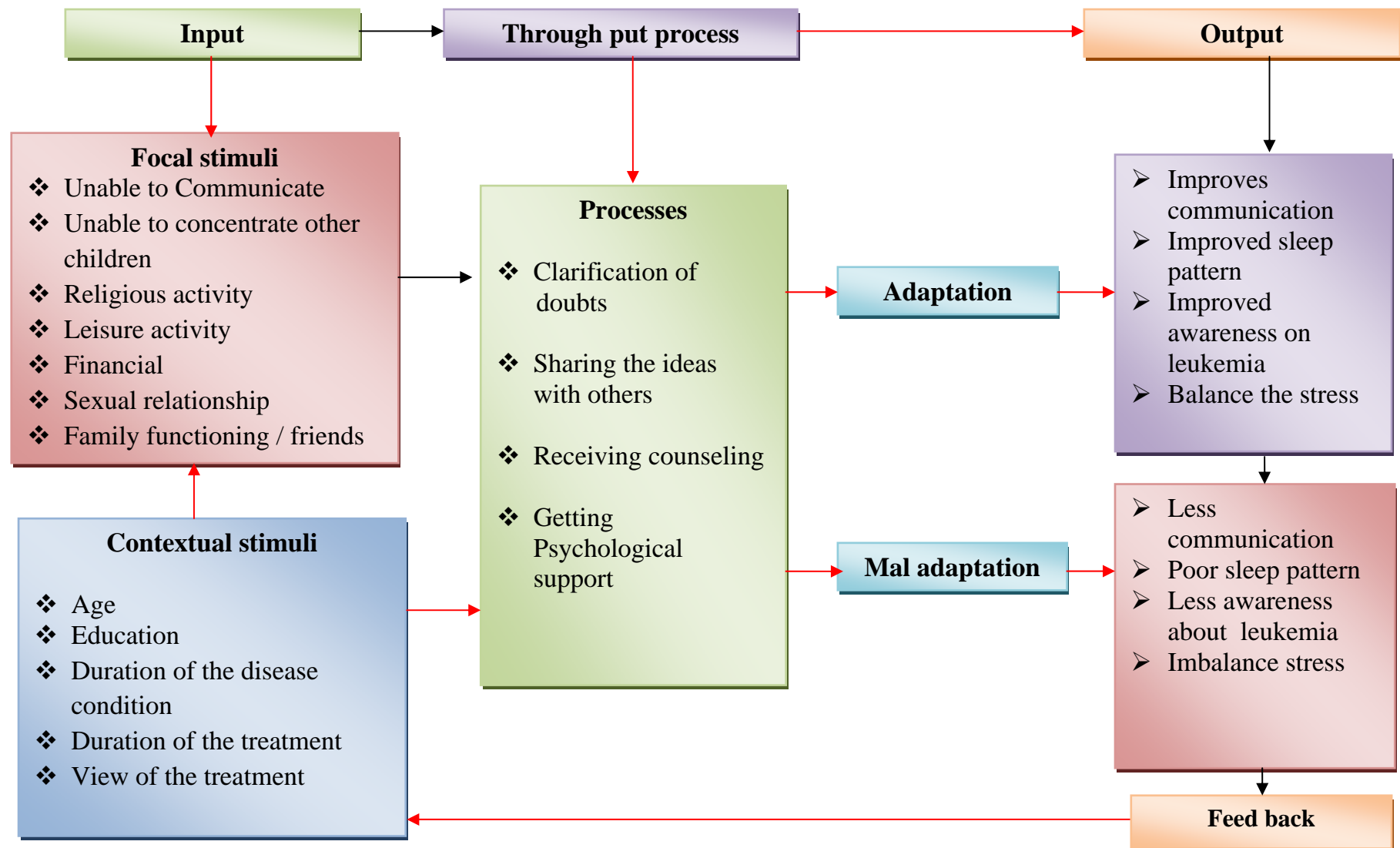
Cognator sub-system consists of input, internal processes and output. It regulates self- concept, role function and inter-dependence. Output is the outcome of the system; when the system is a person, output refers to the person’s behavior.

In this study, the modified theory explained that input as the focal stimuli (unable to communicate, unable to concentrate, religious activity, leisure activity, financial, sexual relationships, family functioning, and contextual stimuli (age, sex, duration of illness, duration of treatment, view of the treatment). The coping mechanisms of the regulator and cognator occurs through clarification of doubts, sharing the ideas with others, receiving counseling and getting psychological support from others.

In the output either the positive or negative adaptation may occur. The positive adaptations are improved communication, maintaining normal sleep pattern, improved awareness, able to balance with stress. The negative adaptations are poor communication, lack of sleep and unable to balance with stress.

**Figure-1** highlights the conceptual framework based on Roy’s adaptation model.





**FIGURE – 1: CONCEPTUAL FRAMEWORK BASED ON MODIFIED ROYS ADAPTATION MODEL (1996)**

# **REVIEW OF LITERATURE**

## **CHAPTER –II**

### **REVIEW OF LITERATURE**

According to **Polit and Hunger (1999)** review of literature is a critical summary of research on a topic of interest generally prepared to put a research problem on context or to identify gaps and weakness on previous studies to justify a new investigation.

The researcher came across with numerous theoretical and empirical literature related to the topic under study. The relevant and related literature that was found useful has been presented as follows.

Review of literature for the present study has been organized under the following headings,

- i. Studies related to awareness on leukemia**
- ii. Studies related to parents stress level**

#### **Studies related to parents awareness on leukemia**

**Mostert S et al, (1989)** conducted a study on comparing childhood leukemia treatment before and after introduction of parental education-programme in Indonesia. A structured parental education program for all parents, poor and prosperous, was introduced to improve access to parental education and donated chemotherapy. They reviewed medical records of 283 children were included in this study, with ALL diagnosed during two periods: before (1997-2002; n=164) and after (2004-2006; n=119) introduction of education program. Data on treatment results and parental socioeconomic status were collected. The program contained video-presentation in hospital, information-booklet, DVD, audiocassette, informed-consent, statement-of-understanding for donated chemotherapy, and complaints-procedure.

After introduction of education program, treatment refusal decreased (14%-2%) and event-free survival increased (13%-29%) significantly in poor patients. Treatment abandonment increased (0%-13%) significantly in prosperous patients.

**Wakeford R (1995)** conducted a study on the risk of childhood cancer from intrauterine and preconception exposure to ionizing radiation. The findings of studies investigated whether exposures to ionizing radiation before birth, either pre / post - conception, increase the risk of childhood cancer have provoked much scientific controversy.

An epidemiological association between the abdominal exposure of pregnant women to diagnostic X-rays and childhood cancer was reported in the 1950s, while an association between the recorded dose of radiation received occupationally by fathers before the conception of their offspring and childhood leukemia was reported only recently in 1990.

In contrast, the association between paternal preconception radiation dose and childhood leukemia has not been confirmed by studies using objectively determined doses. And it is markedly inconsistent with the established body of knowledge on radiation-induced hereditary disease. A causal interpretation of this association has effectively been abandoned by scientific authorities.

**Michelle L et al, (2001)** conducted a study to suggest for improving informed consent, were elicited from 140 parents of children who had been offered participation in a randomized clinical trial for the treatment of their acute leukemia. Four different methods and data collection time points were used with this group of parents, including open-ended interviews within 72 hours after the informed consent conference; follow-up telephone interviews 6 months after diagnosis; focus groups during year 3 of the project; and a parent advisory group on informed consent meeting in year 4.

The suggestions for improving informed consent during the interviews and focus groups related to giving parents more time to make their decision, the

amount and type of information provided, organization of the consent conference, communication style and providing additional materials. During the parent advisory group on informed consent meeting, parents developed specific guidelines for organization of the information that is presented during the consent process that includes 7 major components: timing, sequence, checklist, checking for understanding, anticipatory guidance and segue.

Through the incorporation of parental perspectives that provide an authentic stakeholder voice, research represents a true partnership approach to improving the consent process. Parents provided practical advice for improving informed consent that can be applied to most adult and pediatric patient populations.

### **Childhood cancer takes toll on survivors (health day News 2003)**

Survivors of childhood cancer are much more likely than their healthy siblings to suffer from a variety of health problems when they reach adulthood. The increased risk was particularly pronounced among women, those with lower educational levels and those with low household incomes.

These results, from an unprecedented study of almost 10,000 cancer survivors, because survival rates for childhood cancers are now upwards of 78%, the number of people who have lived five or more years beyond their initial diagnosis is growing. For the first time, scientists and the world can see the long term consequences, which can include second cancer, heart disease, infertility, obesity and psychological distress.

**Tremolada M (2005)** conducted a study about Parental narratives of quality of life in children with leukemia as associated with the placement of a central venous catheter (CVC). Thirty mothers of children with leukemia were included in this study and data were collected by using version of the Eco-cultural Family Interview. Parental narratives were analyzed qualitatively and quantitatively. Four broad dimensions, encompassing 23 sub themes, were identified: child coping ( $\alpha=0.88$ ), child quality of life ( $\alpha=0.72$ ), parental coping ( $\alpha=0.72$ ) and parental trust in the medical care ( $\alpha=0.73$ ).

Regression analyses showed that the number of days from the CVC placement ( $\beta=0.46$ ) and child coping ( $\beta=0.44$ ) significantly predicted children's quality of life, which in turn predicted parental trust in the medical care ( $\beta=0.31$ ).

**Tushti Bhardwaj (2008)** conducted a study on level of awareness about cancer among college youth. In this study, 100 samples were included and samples drawn by using non-probability sampling techniques. The tool used for the study was questionnaire to seek the knowledge and perception of the samples. The results suggest that overall low level of awareness among the samples on various aspects of cancer.

The knowledge score classification shows that none of the respondents qualified for “good knowledge score”, they all fell on the average line. The general awareness about the disease, which could act as benchmark for initiation of further improvement measure was not good. It was seen that youth were also not well aware of the warning signals of cancer. This shows that family in general are not able to identify the initial symptoms and hence the stage gets advanced by the time patient approaches a doctor.

This study emphasizes the need of strong knowledge base about cancer, there is an urgent need of countrywide information, and education and communication campaign about cancer so that general population can easily identify initial symptoms of the disease.

**Cubukcu CE et al, (2008)** conducted a study to assess the experiences of leukemic children and attitudes of parents on dental care. Parental perceptions in the importance of dental care and preferences with regard to its provision while profiling the level of dental health knowledge of parents of leukemia children were elicited. The setting was the Pediatric Dental Care Unit located in Medical Faculty. Data were collected by means of a structured interview, employing a questionnaire. Level of knowledge on both dental facts and preventive dentistry of the participants was insufficient.

Major source of dental care was the resident pediatric dentist both in prior to (78.2%) and following (100%) diagnosis. Tooth extraction (17.6%) was the only treatment provided prior to diagnosis. Following diagnosis (69%) of these children had received operative dental treatment.

**Sitairesmi M N (2008)** conducted a study on attitude of health-care providers towards childhood leukemia patients with different socio-economic status. Treatment results differ significantly between poor and prosperous children with leukemia in Indonesia. The objective of this study was to determine whether parental socio-economic status influences beliefs, attitude, and behavior of **health-care providers (hcp)** treating childhood leukemia in Indonesia.

A self-administered semi-structured questionnaire was filled by 102 hcp (69 doctors, 28 nurses, 2 psychologists, 2 hematology technicians, and one administrator). Most hcp (98%) asked parents about their financial situation. The decision to start treatment was influenced by parental socio-economic status (86%), motivation of parents (80%), and motivation of doctors (76%). Health-care providers stated that prosperous patients comply better with treatment (64%), doctors comply better with treatment for the prosperous (53%), most patients could not afford to complete treatment (58%), less extensive explanations were given toward poor families (60%) and communication is impeded by differences in status (67%).

When dealing with prosperous families a minority of hcp stated that they paid more attention (27%), work with greater accuracy (24%), took more interest (23%) and devote more time per visit (22%). Most hcp denied differences in the quality of medical care (93%) and the chances of cure (58%) between poor and prosperous patients. Beliefs, attitude, and behavior of hcp toward poor versus prosperous patients appeared to differ. These differences may contribute to the immense drop-out rate and slight chances of survival among poor patients with leukemia in developing countries.

## **Study related to stress**

**Rohrer RL (1995 - 2005)** conducted a study to explore unique role of parental visitors of children with cancer at the Children's Hospital of Pittsburgh. Using oral interviews with parents, medical and psychosocial staff the data was collected, and the study explores the experiences of parents while in hospital with their children and the social, emotional, financial and family issues they confronted during these admissions. Parents in their stories identified the various roles they assumed as their children experienced illness, treatment, side effects and psychosocial issues.

**Emma Kinderziekenhuis (1998)** conducted a study about emotions, coping and the need for support in families of children with cancer a model for psychosocial care. In the case of childhood cancer, the personal threats are severe for the child, the parents and other family members. For the child, there is the threat to physical integrity, safety, security, and above all, to life. For the parents, there is the threat of losing the child. However, a number of studies have shown that psychopathological disturbances are rarely found in children with cancer or their parents.

They conclude from that most children and parents use coping strategies that protect them from developing psychopathology. In organizing support for families with a child with cancer, much can be learned from children's and parent's perceptions and reactions. When problems of adjustment arise, a thorough analysis of how children and parents perceive their situation, as well as an extensive analysis of their coping efforts, is necessary to direct effective supportive actions. A psychosocial support model is proposed which can be helpful in interpreting these emotions and coping strategies.

A prospective study conducted by **Gold beck L ( 2001 )** to assess the Parental coping with the diagnosis of childhood cancer, gender effects, dissimilarity within couples, and quality of life. A total of 108 parents out of 54 complete families participated in this study. Twenty-five families had a child newly diagnosed with cancer, 29 families had a child newly diagnosed with



juvenile diabetes or epilepsy. The Coping Health Inventory for Parents, the Trier Coping Scales, and the Ulm Quality-of-Life Inventory for parents were employed 1-2 weeks after diagnosis and again 10-12 weeks after diagnosis.

In face of childhood cancer, parents develop more rumination, defense, and information seeking, and less social support seeking strategies compared to the control group. Mothers report more frequent and more effective coping compared with fathers, but mothers and fathers do not differ in their self-reported quality of life.

A longitudinal study was conducted by **Mary Best et al, (2001)** to assess the Parental Distress during Pediatric Leukemia and Posttraumatic Stress Symptoms (PTSS) after treatment ends. Hundred and Thirteen parents of children treated for leukemia who previously participated in a study of procedural distress during treatment were participated in this study.

Data included that parental self-report questionnaires completed during treatment and after treatment. The results suggest that anxiety during treatment to be a significant predictor of later PTSS for mothers, but not fathers. Anxiety, self- efficacy; post traumatic growth and length of time since treatment ended were associated with parental avoidance.

This study concludes that the highly anxious parents are at risk for PTSS and may benefit from approaches that decreases anxiety during treatment and afterward.

**Eapen V et al, (2003)** conducted a study to determine the psychosocial factors and illness of variables associated with children's and parents perceptions of and ways of coping with cancer in the Arab Emirates. Thirty eight childhood cancer patients aged 5-15 years were included in this study. Coping was studied in relation to socio-demographic variables and self-perception in terms of competence, behavior and self-worth.

Less optimal coping was found to be associated with poor family communications and lack of sharing/expression of emotions ( $P=0.005$ ), presence

of behavioral and emotional problems in the child ( $P=0.008$ ) and parental lack of hope ( $P=0.001$ ). No association was found with gender, parental education or occupation, socioeconomic status or child's self-perception including global estimation of self-worth.

Findings suggest that parental hope and both social and family communication are integral to helping patients and families cope with the illness experience.

**Saran P et al, (2007)** conducted a study about, coping and adaptation of 39 children (6-12 years) to Acute Lymphoblastic Leukemia was studied during the first remission with a projective technique-Children's Apperception Test (CAT-S). Seventy seven percent of the children gave adequate responses.

Among these, disease awareness was present in 96%, expectation of a favorable outcome was held by 70%, though 61% evidenced emotional distress. Children's psychiatric morbidity was found to be associated with non-response to CAT-S, to anxiety related themes, and negatively with ability to maintain an expectation of a positive outcome.

**Ljungman G (2008)** conducted a longitudinal study on post traumatic stress disorder (PTSD) among parents of children on cancer treatment. A longitudinal design with assessments at one week (T1), two (T2), and four (T3) months after the child's diagnosis was used. Two hundred and fourteen parents (107 mothers, 107 fathers) participated at T1-T3. The PTSD Checklist Civilian (PCL-C), a self-report screening instrument for PTSD, was answered by parents over the telephone.

According to the PCL-C symptom criteria method 33%, more mothers than fathers, score as potential cases of acute stress disorder (ASD) at T1, whereas 28% as potential cases of PTSD at T2 and 22% at T3.

The levels of acute and posttraumatic stress symptoms show a linear, descending pattern, and mothers report higher levels than fathers. Half of the

parents who score as potential cases of ASD a week after the child's diagnosis score as potential cases of PTSD four months later.

The study of **Bennett Murphy LM (2008)** examined the role of fathers caring for children with cancer. Psychological adjustment, coping, and work patterns of mothers and fathers were described. Twenty fathers of children with cancer were compared with 20 mothers of children with cancer and 20 control fathers of healthy children. Questionnaire data were collected regarding coping, parental adjustment, child adjustment, and family involvement.

The result showed that fathers did not differ from mothers or control fathers in terms of psychological adjustment or coping. However, fathers of children with cancer spent more hours at work and more hours caring for children than did control fathers. Paternal adjustment was significantly related to child adjustment only when the child had cancer. Coping was related to work outside the home for fathers and adjustment for mothers. Models of family adaptation may be different for fathers and mothers. Treatment teams must attend to the unique needs of fathers.

**Norberg AL (2008)** conducted a study about parent distress in childhood cancer a comparative evaluation of post traumatic stress symptoms (PTS; cognitive intrusions, avoidance, arousal), depression and anxiety.

Data from a clinical sample of posttraumatic stress disorder (PTSD) patients and parents of healthy children were used for comparisons.

The Impact of Events Scale (IES-R) was used for assessing PTS symptoms, and self-report scales for anxiety and depression. Elevated stress and generic distress varied as a function of time from diagnosis. Up to 12% of parents for whom >5 years had passed since diagnosis still reported equally or more intrusive thoughts, avoidance and arousal when contrasted to patients suffering from PTSD.

Parents of recently diagnosed children had more cancer-related intrusive thoughts than those of long-term survivors. Heightened anxiety and depression was most prominent in mothers and fathers up to 2.5 years after diagnosis.

**John Wiley and Sons (2008)** research has done in developing countries on the emotional impact experienced by families who have a child diagnosed with leukemia. The 51 children in the study were under 15 years and being treated for leukemia in hospitals affiliated with the Mexican social security institute (IMSS) where their parents were interviewed using a questionnaire to ascertain their emotional responses to the illness. The data was analyzed and reported in five domains perceived illness psychological impact.

A strengthening of family bonds was found the most common response (82.4%). The second most common responses were concern for the expenses incurred by the illness and the time dedicated to caring for the sick child (both 78.4%). It is especially important to assess families with manager social and financial resources as to their emotional responses to life-threatening illness because these limitations impose greater burdens and make coping more difficult. Psychosocial interventions key are to ensuring adequate treatment of the child in these circumstances.

This review of literature gave an in depth knowledge which are related to the research problems of awareness of parents on leukemia and their stress. The review of literature helped the investigator to select the settings, to understand the problem of awareness on leukemia, and their stress, and to design the present study.

# **METHODOLOGY**

## **CHAPTER- III**

### **METHODOLOGY**

Methodology of research organizes all the components of the study in a way that is most likely to lead to valid answer to the problems that have been posed (**Burns and Grove 2002**). It refers to various logical steps that are generally adopted by the investigator in studying the research problem.

This chapter deals with the methodology to assess the awareness on leukemia among parents and their level of stress in having a child undergoing leukemic treatment. It includes research design, setting, population, sample, and sampling technique, sampling criteria, description and construction of tool, pilot study, data collection procedure and data analysis.

#### **RESEARCH DESIGN**

A descriptive survey approach was adopted in this study. A descriptive study is designed to gain more information about characteristics with in a particular field of study. Its purpose is to provide a picture of a situation as it naturally happens. A descriptive design may be used to develop theories, identify problems with current practice, justify the current practice, make judgments or determine what other practitioners in similar situation are doing.

For the present study, a descriptive survey approach was considered most appropriate as the purpose of the study was to gain an understanding of the parent's knowledge on leukemia and their level of stress.

#### **RESEARCH SETTINGS**

The study was conducted in the oncology outpatient department of a selected private hospital at Coimbatore.

This hospital has 450 beds with multispecialty medical services. This hospital has oncology and onco surgical department and a separate low count unit, hospice centre, rehabilitation centre etc.

There are five oncologic outpatient departments headed by one oncologist expert; each outpatient department has a one auxiliary nurse. On an average 20 patients receive chemotherapy per day.

Service to leukemia children in the outpatient department is yoga, spiritual therapy, play therapy and counseling to the parents and children.

Here all the cancer patients were treated by medical, radiological and surgical interventions. Every month more than 100 patients receive treatment in the outpatient department.

## **POPULATION**

The population of the study included all the parents aged 20 to 50 years attending the oncology outpatient department of the selected hospital with their leukemic children for treatment at the time of the study.

## **SAMPLE**

The sample consisted of 35 parents (35 fathers and 35 mothers) with leukemic child under treatment, selected from the population based on the sampling criteria.

## **SAMPLING TECHNIQUE**

A convenient non random sampling method was adopted, according to the availability of the sample.

## **SAMPLING CRITERIA**

### **Inclusion criteria:**

1. Parents in the age group of 20 to 50 years.
2. Parents with children in the age group 5 to 15 years undergoing treatment for leukemia.
3. Parents who were able speak and understand Tamil or English.

**Exclusion criteria:**

1. Children above 15 years.
2. Parents who were not willing to participate

**DESCRIPTION OF THE TOOL**

The tool used in this study was an interview schedule with three parts (Refer Appendix- vi).

**PART -I**

Part-I was designed to collect demographic data of the fathers and mothers (age, education, occupation, family and income of parents) and data on children (numbers of children, birth order, age of the child, duration of illness, duration of treatment and school attendance).

**PART-II**

This part was designed to assess the awareness of parents on leukemia. There were nine questions focused on the meaning, reasoning, signs and symptoms, diagnosis, treatment and care of child with leukemia. Under each of these questions there were 3 – 10 sub questions of multiple response type except for “care of the child” with leukemia had ten dichotomous questions.

**PART-III STRESS SCALE**

This part was designed to assess the level of stress of the parents having a leukemic child.

There were physiological and psychological stress items, worry about child condition stress items, and family functions items statements organized under a likert type five point scale was provided to rate the responses. Strongly agree-5 agree-4, neutral-3, disagree-2, strongly disagree-1.



## **SCORING AND SCORE INTERPRETATION:**

### **Awareness on leukemia**

#### **Scoring**

Meaning and reason	20
Signs and symptom and diagnosis	14
Treatment	16
Care of the child	10
The minimum score was 0 and maximum score 60	

#### **Score Interpretation**

<b>Score</b>	<b>percentage</b>	<b>Interpretation</b>
0-20	0-30	Little
21-40	35-67	Somewhat extent
41-60	68-100	Greater extent

#### **Stress scale**

##### **Likert five point scale                      score**

Strongly agree	5
Agree	4
Neutral	3
Disagree	2
Strongly disagree	1

The minimum score was 0 and maximum score 80

#### **Scoring and score Interpretations**

<b>Items</b>	<b>Minimum Score</b>	<b>Maximum Score</b>
Physical and physiological	6	30
Worry about child condition	6	30
Family functioning	4	20

### **Score interpretation**

<b>Score</b>	<b>percentage</b>	<b>interpretations</b>
0-26	0 - 32.5	Mild stress
27-53	33.75 - 66.25	Moderate stress
54-80	67.50 - 100	Severe stress

### **CONSTRUCTION OF TOOL**

The tool was developed based on the objectives of the study, discussion with experts and parents and review of literature.

### **CONTENT VALITY**

The tool along with the objectives and criteria were submitted to one medical expert, one clinical psychologist and three nursing experts. The three nursing experts hold a Masters degree in Child health nursing specialty working as a Reader in two private nursing colleges. The Medical Expert (MD, pediatrician) is a consultant in one of the private hospital in Coimbatore with more than 5 years of experience. The Clinical Psychologist (PhD) is Assistant Professors in one of the private college with more than 5 years of experience. According to the suggestions of experts few questions were modified in the tool prepared for pilot study.

### **RELIABILITY**

The reliability of the three sub scales of the rating scale was established by split half method. Correlation co- efficient was calculated by Guttman spit half method.

The obtained “r” value was 0.8 for awareness of parents on leukemia, and 0.7 for parents stress scale, which confirmed that there was high positive correlation and internal consistency of the tool.

## **PILOT STUDY**

A pilot study was conducted in the oncology outpatient department of the same selected hospital at Coimbatore. A formal permission was obtained from the Administrative Officer and Head of the Department of Oncology unit. The purpose of the study was explained to the concerned head of the department. After clarifying each questions regarding the study one room was allotted for conducting the interview.

Ten parents who came to the outpatient department with their children for review were selected by convenience based on inclusion criteria. Parents were made to sit comfortably in the interview room and explained the purpose of the study. Those who were willing to participate were individually met.

After obtaining their rapport and after a self introduction, the data on demographic characteristics of parents and data on children, awareness on leukemia, and their stress level were collected by interview technique. The duration of pilot study was ten days.

The result of the pilot study showed that, the tool and technique adopted were adequate.

## **DATA COLLECTION PROCEDURE**

A formal written permission was obtained from the oncologist expert of a selected hospital. The investigator also familiarized with the medical officers and staff incharge of the oncology unit and explained the purpose of the study. Every day the investigator visited the hospital to confirm the availability of the cases.

Before commencement of the data collection, investigator met the receptionists and nurses who were working in oncology outpatient department in order to develop good rapport and obtain cooperation to collect the data.

The parents who came to the outpatient department for review on the basis of inclusion criteria were selected by convenient sampling technique. After the sample is selected, a brief introduction about self and study intent was given. Strict confidentiality was ensured. After obtaining their rapport and willingness, the data regarding the demographic characteristics, data on children, awareness on leukemia and their stress level by using questionnaire and likert scale. Parents were interviewed separately (fathers and mothers). The parents were requested not to share the information with others regarding interviews. The investigator thanked the parents after the interview. The researcher stayed in the hospital from 8.00 am to 4.00 pm, to collect the data. The average time taken for completion of the interview was 30 minutes for each individual.

Using the same procedure data was collected from 35 parents (fathers and mothers) during daytime (8.00-4.00). Total data collection period was 31days from June 29 to July 29 - 2009.

## **PLAN FOR DATA ANALYSIS**

The data obtained would be analyzed in terms of the study using descriptive and inferential statistics.

## **DESCRIPTIVE STATISTICS**

Frequency, percentage distribution were used to analyze demographic variables, to assess the parents awareness on leukemia and their stress level.

Mean standard deviation and mean score percentages were used to analyze the demographic data, level of awareness on leukemia and stress scale with regard to parents having leukemic child.

## **INFERENTIAL STATISTICS**

Chi-square was used to find out the association between the awareness on leukemia with selected variables of the parents and the association between levels of stress with selected demographic variables of the parents with regards to leukemic child.

Unpaired 't'- test was used to determine the significance between the parents awareness on leukemia and their level of stress, a child undergoing to treatment in a selected hospitals.

# **ANALYSIS AND INTERPRETATION**

## **CHAPTER IV**

### **ANALYSIS AND INTERPRETATION**

**Kerlinzer (1976)** has described analysis as the “categorizing, ordering, manipulating and summarizing of data to obtain answers to be used in research Hypothesis questions”.

This chapter deals with the analysis and interpretation of the data gathered from 35 fathers and 35 mothers having leukemic children with regard to their awareness about leukemia and the level of stress. The data have been presented comparatively for the fathers and mothers.

#### **Section – I    Demographic characteristics of the sample**

This section deals with the demographic profile of the couples (Parents) in relation to their age, education, occupation and monthly Income per month in frequency and percentage.

#### **Section – II    Awareness of parents on leukemia**

The view of fathers and mothers with regard to leukemia has been presented in three levels of awareness (Little, Somewhat, Great) in frequency and percentage.

Awareness of fathers and mothers in three aspects of leukemia, and on individual item such as related to the three aspects has been presented in mean and level of significance by statistical test.

#### **Section – III    Stress of parents having leukemia child**

This section deals with the stress of parents having leukemic children in three areas of stress physiological and psychological stress, worry about child

condition and family functioning and overall stress in frequency percentage and mean score. The level of significance was determined by using statistical tests.

The views of fathers and mothers have been presented the three areas of stress on a three point scale by reducing the five point scale in to three point scale 1. Strongly agree and agree, 2. Neutral, 3.Strongly disagree and disagree and the weighted score.

#### **Section – IV Association of demographic variables of parents and children with awareness and Anxiety on leukemia**

This section presents,

1. Association of demographic variables of parents with their level of awareness on leukemia.
2. Association of demographic variables of parents with their level of stress.
3. Association of demographic variables of children with parents level of awareness on leukemia.
4. Association of demographic variables of children with parent's level of stress.



**SECTION- A: THE DEMOGRAPHIC VARIABLES OF SAMPLE**

**TABLE – I**

**FREQUENCY AND PERCENTAGE DISTRIBUTION OF PARENTS  
ACCORDING TO THE DEMOGRAPHIC VARIABLES**

S. No	Demographic Variables	Father N = 35		Mother N = 35	
		Frequency	%	Frequency	%
1	<b>Age in Years</b>				
	a 20 – 30	-	-	12	34.28
	b 30 – 40	22	62.85	22	62.85
	c 40 – 50	13	37.14	1	02.85
2	<b>Education</b>				
	a Illiterate	4	11.42	14	40.00
	b Primary	4	11.42	3	08.57
	c Middle	9	25.71	3	08.57
	d Secondary	3	08.57	7	20.00
	e College	15	42.85	8	22.85
3	<b>Occupation</b>				
	a House Wife	-	-	30	85.71
	b Laborers	13	37.14	2	05.71
	c Business	9	25.70	-	-
	d Agriculture	5	14.28	1	2.85
	e Professional	6	17.14	-	-
	f Any other	2	05.71	2	05.71
4	<b>Income per Month in Rs.</b>				
	a < 5,000	16	45.71	3	8.57
	b 5000 – 10000	6	17.14	1	2.85
	c 10000 – 15000	4	11.40	-	-
	d Above 15000	9	25.70	1	2.85

**Table-I** presents the frequency and percentage distribution of children characteristics.

**Age:**

The age of the parents ranged from 20 – 50 years. Majority of the parents both fathers and mothers (62.85 %) were in the age group of 30 – 40 years, 13 fathers (37.14 %) were between 40 – 50 years where as 12 mothers (34.28 %) were in the age group of 20 – 30 years, and one mother (02.85 %) was between 40 – 50 years of age .

**Education:**

The parents showed different level of education 15 fathers (42.85%) and 8 mothers (22.8%) were graduates. 14 mothers (40%) and 4 fathers (11.4%) were illiterates. The remaining 16 fathers and 13 mothers had education either at primary, middle or secondary level.

**Occupation:**

Majority of mothers (85.71 %) were house wives, among 13 fathers (37.14%) were working as laborers, the rest of the fathers were engaged in different occupation such a professional, agriculture and in other areas (5 - 25.7%). Among the mothers 1-5 (2.8 – 5.7 %) were laborers, doing agriculture or working in other areas.

**Income:**

16 fathers (45.71 %), 8.57% mothers were earning an income less than Rs.5000/-, 10 fathers (11.40 – 14.20%) were earning a monthly income of Rs.5000/- to 15000/-. 9 fathers (25.70 %) had an earn income above Rs.15000/- whereas very few mothers (2.85 %) earned monthly income above Rs.15000/- .

**TABLE – II**

**FREQUENCY AND PERCENTAGE DISTRIBUTION OF CHILDREN  
ACCORDING TO DEMOGRAPHIC VARIABLES**

**N=35**

<b>S. No</b>	<b>Demographic Variables</b>	<b>Frequency</b>	<b>%</b>
<b>1</b>	<b>Number of Children in the Family</b>		
	a One	8	22.86
	b Two	18	51.46
	c Three	6	17.14
	d Four	3	8.57
<b>2</b>	<b>Age in Year</b>		
	a 5 – 8	23	65.71
	b 9 – 12	10	28.57
	c 13 – 15	2	5.71
<b>3</b>	<b>Birth Order</b>		
	a First Child	23	65.71
	b Second Child	12	34.29
<b>4</b>	<b>Going to School</b>		
	a Yes	10	28.57
	b No	25	71.43
<b>5</b>	<b>School Attendance</b>		
	a Regular	-	-
	b Irregular	10	28.57

**Table-II** presents the frequency and percentage distribution of children based on demographic variables.

The number of children in the family ranged from one to four. Eighteen (51.46%) families had two children, 8 families (22.86%) with one child, 6 families (17.14 %) had three children and the rest 3 (8.57 %) had four children.

The age of children ranged from 5 to 15 years. Majority of the children 23 (65.71 %) were in the age group 5 to 8 years, 10 (28.57 %) children were in the age group of 9 to 12 years and the rest 2 (5.71 %) children were between 13 – 15 years of age.

The order of birth of 23 (65.71 %) children were first and remaining 12 (34.29) were second child in the family based on the birth order.

Only few children 10 (28.57 %) were going to school and the rest of 25 (71.42 %) children were not going to school due to the illness. All the children going to school were irregular due to illness, treatment and follow-up in hospital.

**TABLE – III**  
**FREQUENCY AND PERCENTAGE DISTRIBUTION OF CHILDREN**  
**BASED ON ILLNESS AND TREATMENT**

**N = 35**

<b>S. No</b>	<b>Characteristics</b>	<b>Frequency</b>	<b>%</b>
<b>1</b>	<b>Duration of Illness</b>		
	a. Less than Six Month	21	60.00
	b. Six Month to One Year	06	17.14
	c. Above One Year	08	22.86
<b>2</b>	<b>Treatment</b>		
	a. Chemo Therapy	35	100.00
	b. Radiation Therapy	-	-
	c. Surgery	-	-
<b>3</b>	<b>Duration of Treatment</b>		
	a. Recently Started	1	02.86
	b. Less than Six Month	26	74.29
	c. Six Month to One Year	-	-
	d. Above One Year	8	22.86

**Table-III** presents the frequency and percentage distribution of children illness and treatment.

Majority of children (60 %) were suffering from leukemia for less than six months, 6 (17.14 %) children from six months to one year and the rest of children 8 (22.86 %) were suffering for more than one year. All the children 35 (100 %) were undergoing Chemo Therapy.

It was noted that 26 (74.29 %) children were undergoing treatment leukemia for less than six months, 8 (22.86 %) children were undergoing treatment for more than one year and only one child started treatment very recently.

## **SECTION – B: AWARENESS OF PARENTS ON LEUKEMIA**

**TABLE –IV**

### **FREQUENCY AND PERCENTAGE DISTRIBUTION OF PARENTS ACCORDING TO OVERALL AWARENESS ON LEUKEMIA**

**N=70**

<b>S. No</b>	<b>Variables</b>	<b>LEVEL OF AWARENESS</b>			
		<b>Some what</b>		<b>Great extent</b>	
		<b>Frequency</b>	<b>%</b>	<b>Frequency</b>	<b>%</b>
1	Father	3	9.00	32	91.00
2	Mother	4	11.00	31	89.00

**Table-1V** presents the frequency and percentage distribution of parents overall awareness on leukemia.

Thirty two fathers (91.0%) and 31 mothers (89.0 %) had a high level of awareness regarding leukemia. Only three fathers (9.0 %) and 4 mothers (11.0%) showed a moderate level of awareness with regard to leukemia.

The table clearly shows more awareness of fathers and mothers regarding leukemia are almost similar.

**Figure- 2** highlights the overall awareness of parents on leukemia.

**TABLE V**

**MEAN AWARENESS SCORE, STANDARD DEVIATION OF FATHERS  
AND MOTHERS WITH REGARD TO ITEMS RELATED TO MEANING  
AND REASON ON LEUKEMIA AND SIGNIFICANCE**

**N=70**

S. No	Items	Maximum score	Father (N = 35)			Mother (N = 35)			Un paired t- test, Sp= <0.05,
			MS	SD	Mean %	MS	SD	Mean %	
1	Meaning of cancer	5	2.31	1.03	46.28	1.88	1	37.60	1.01 NS
2	Meaning of leukemia	3	2.02	0.22	67.33	2.11	0.12	70.33	0.23 NS
3	Reason for leukemia	12	9.05	2.29	75.41	6.45	2.49	53.75	4.07*
4	Signs and symptoms of leukemia	9	8.28	1.17	92.0	4.74	1.01	94.84	0.18 NS

**\*Significant**

**NS- Non Significant**

**Table value = 1.67**

**Table-V** presents the mean awareness of parents with regard to meaning of cancer, reason and manifestations of leukemia.

The mean awareness score of fathers on signs and symptoms of leukemia was high 92.0%, on reason for leukemia was 75.4%, and meaning of cancer and leukemia ranged between 46.0% - 67.0%.

Mothers also scored very high 94.84% on the awareness of signs and symptoms of leukemia similar to fathers. The mean score of mothers regarding reason for leukemia was low 53.75% compared to fathers (75.41%).

Statistically there was no significant difference in the mean score of fathers and mothers with regard to meaning of cancer, leukemia and signs and symptoms of leukemia. So the hypothesis ( $H_{01}$ ) is accepted.

However there was a significant difference between the fathers and mothers awareness with regard to reason for leukemia (t-test value - 4.07, df-68,  $p < 0.05$ ). Hence the hypothesis rejected.

**Figure-3** highlights the mean score of parents awareness on meaning, reasoning, signs and symptoms of leukemia in percentage.



**TABLE – VI**

**MEAN AWARENESS SCORE AND STANDARD DEVIATION OF  
FATHERS AND MOTHERS WITH REGARD TO ITEM RELATED TO  
DIAGNOSIS AND TREATMENT ON LEUKEMIA AND THEIR  
SIGNIFICANCE**

**N=70**

S.No	Items	Maximum score	Father (N = 35)			Mother (N = 35)			Un paired t-test, value
			MS	SD	Mean %	MS	SD	Mean %	
i.	Diagnosis of leukemia	5	4.71	0.69	94.28	4.74	1.01	94.84	0.18 NS
ii.	Treatment	7	5.28	1.06	75.42	5.14	0.81	73.46	1.25 NS
iii.	Blood transfusion	4	3.62	0.31	90.5	3.4	0.42	85	0.75 NS
iv.	Advantage of treatment	5	4.85	0.42	97.14	4.65	0.50	93	0.51 NS
v.	Care of the child	10	9.14	0.82	91.40	9.22	0.74	92.28	0.35 NS

\* Significant      NS- Non Significant      Table value = 1.67

**Table-VI** presents the mean awareness score, standard deviation and level of significance of parents in diagnosis, treatment and care of the child with leukemia.

The mean score of the fathers regarding the awareness on advantage of treatment was high that is 97.14%, followed by 94.28% in diagnosis of leukemia, whereas awareness in the aspects of blood transfusion and care of the child obtained a score of 90.50% and 91.40% respectively. Lowest score obtained was awareness of treatment (75.42%).

Comparatively for mothers awareness score was high for (94.84%) diagnosis of leukemia, (93.0%) for advantage of treatment and (92.28%) care of the child. Majority (85%) of the mothers had awareness on blood transfusion for leukemic child, lowest score was obtained for awareness on treatment (73.46%).

This table concludes that the fathers and mothers had more awareness in diagnosis and advantage of treatment of leukemia.

Statistically there was no significant difference in the mean awareness score of diagnosis, treatment and care of the leukemic child between the fathers and mothers. So the hypothesis (**H<sub>01</sub>**) is accepted.

**Figure-4** highlights mean score of parents awareness in diagnosis, treatment and care of the child on leukemia in percentage.

**TABLE- VII**

**MEAN AWARENESS SCORE AND STANDARD DEVIATION OF  
FATHERS AND MOTHERS IN THE THREE ASPECTS OF LEUKEMIA  
AND LEVEL OF SIGNIFICANCE**

**N=70**

<b>S. No</b>	<b>Aspects of leukemia</b>	<b>Maximum score</b>	<b>Fathers (N = 35)</b>			<b>Mothers (N = 35)</b>			<b>Un paired t- test, value at</b>
			<b>MS</b>	<b>SD</b>	<b>Mean %</b>	<b>MS</b>	<b>SD</b>	<b>Mean %</b>	
i.	Meaning and reasoning	29	21.17	3.7	73.0	18.6	3.5	64.13	3.2*
ii.	Diagnosis and treatment	21	18.02	1.7	85.80	18.08	1.8	86.09	0.001NS
iii.	Care of the child	10	09.08	0.92	90.80	09.25	0.74	92.50	0.32 NS

**\* Significant**

**NS - Non significant**

**Table value = 1.67**

**Table-VII** presents the mean awareness score, standard deviation, and level of significance of parents awareness on leukemia in various aspects.

In care of child, fathers obtained very high mean score of 90.80%, 85.80% was calculated based on the awareness on diagnosis and treatment and minimum score was 73.0% on meaning and reasoning. For the mothers, similar to fathers, the mean score was high in care of the child (92.50%), diagnosis and treatments obtained score was 86.09%, and it was 64.13% was obtained for the meaning and reasoning.

This table concludes that the fathers and mothers had more awareness on the aspects care of the child and diagnosis and treatment.

There was a significant difference between the parents (fathers and mothers) meaning and reasoning of leukemia ( $t=3.2$ ,  $df=68$ ,  $p<0.05$ ).

There was no significant difference in the mean score of diagnosis and treatment of leukemia. So the hypothesis (**H<sub>01</sub>**) is accepted.

**Figure- 5** highlights the awareness of the fathers and mothers in the three aspects of leukemia in percentage.

**TABLE – VIII**

**MEAN AWARENESS SCORE AND STANDARD DEVIATION OF  
FATHERS AND MOTHERS IN THE OVERALL AWARENESS OF  
LEUKEMIA AND LEVEL OF SIGNIFICANCE**

**N=70**

<b>S. No</b>	<b>Variables</b>	<b>Maximum score</b>	<b>Mean score</b>	<b>Standard deviation</b>	<b>Mean Percentage</b>	<b>Un paired t- test, value at</b>
i.	Father (N = 35)	60	48.27	6.32	80.45	1.21 NS
ii.	Mother (N = 35)	60	46.48	6.04	77.46	

**\* Significant      NS- Non Significant      Table value = 1.67**

**Table- VIII** presents the mean score, standard deviation and level of significance of parents over all awareness on leukemia.

Regarding the overall awareness on leukemia, the mean score for fathers was 80.45%, and for mothers was 77.46%.

Though the mean score of the fathers was higher than mothers, no significant difference was noted between the awareness of fathers and mothers with regard to leukemia (t- test-1.21, df-68,  $p < 0.05$ ). So according to the

hypothesis (**H<sub>01</sub>**), there was no significant difference between the awareness of fathers and mothers having leukemic child.

This table concludes that both fathers and mothers have more or less equal stress on leukemia.

**Figure- 6** highlights the mean score of fathers and mothers in overall awareness on leukemia in percentage.

#### **SECTION – C OVER ALL STRESS**

**TABLE – IX**

#### **FREQUENCY AND PERCENTAGE DISTRIBUTION OF PARENTS ACCORDING TO LEVEL OF STRESS IN VARIOUS AREAS**

**N=70**

<b>S. No</b>	<b>Items</b>	<b>Father (N = 35)</b>						<b>Mother (N = 35)</b>					
		<b>Mild stress</b>		<b>Moderate stress</b>		<b>Severe stress</b>		<b>Mild stress</b>		<b>Moderate stress</b>		<b>Severe stress</b>	
		<b>F</b>	<b>%</b>	<b>F</b>	<b>%</b>	<b>F</b>	<b>%</b>	<b>F</b>	<b>%</b>	<b>F</b>	<b>%</b>	<b>F</b>	<b>%</b>
i.	Physical and Psychological stress	-	-	21	60.0	14	40.0	-	-	5	14.28	30	86.0
ii.	Worry about child condition	-	-	15	43.0	20	57.0	-	-	8	23.0	27	77.0
iii.	Family functioning	5	14.0	24	69.0	6	17.0	3	9.0	29	83.0	3	9.0

**Table-IX** presents the frequency and percentage of the parents according to level of stress in three areas.

In the area of physical and psychological stress, majority (86.0%) of the mothers had severe stress compared to fathers (40%).

Majority (77.0%) of the mothers had severe stress regarding worry about child condition, compared to (57.0%) fathers.

Majority of the fathers (69.0%) and mothers (83.0%) had moderate stress regarding family function.

This table concludes that the mothers have more severe stress in physical and psychological stress and worry about child's condition, when compare to fathers.

**TABLE – X**  
**FREQUENCY AND PERCENTAGE DISTRIBUTION OF FATHERS AND MOTHERS**  
**WITH REGARD TO PHYSICAL AND PSYCHOLOGICAL STRESS IN THREE POINT SCALE.**

**N=70**

S. No	Items	Father (N = 35)						Weighted Score	Mother (N = 35)						Weighted score
		SA		N		SD			SA		N		SD		
		F	%	F	%	F	%		F	%	F	%	F	%	
i.	I have no appetite	21	60.0	11	31.4	3	8.57	88	35	100	-	-	-	-	105
ii.	I get tired very easily	3	8.57	17	48.57	15	42.85	67	8	22.85	19	54.28	8	22.85	94
iii.	I am not able to concentrate	15	42.85	4	11.42	16	45.71	69	22	62.85	7	20	6	17.14	86
iv.	I am not able to sleep well	35	100	-	-	-	-	105	34	97.14	1	2.85	-	-	104
v.	I get irritated easily	7	20.0	16	45.71	12	34.28	65	12	34.28	13	37.14	10	28.57	72
vi.	I am not able to control my emotions	14	40.0	13	37.14	8	22.85	76	35	100	-	-	-	100	105

**Table- X** Presents frequency and percentage distribution of parents on three point scale with regard to physical and psychological stress.



All fathers (100%) strongly agree that they were unable to sleep, 21 fathers (60%) had no appetite, 15 fathers (42.85%) were 'unable to concentrate' and 14 fathers (40%) are 'unable to control their emotions'. Seventeen fathers (48.5%) were neutral regarding getting 'tired very easily'. Sixteen fathers (45.71%) strongly disagreed that they were 'not able to concentrate', 15 fathers (42.85%) strongly disagreed that they get tired very easily. All the negative views in the order of priority of weighted score were 4, 1 and 6. The first rank was given to the item not able to sleep well. The item least in the order was getting irritated easily.

All the mothers (100%) strongly agreed that they had 'no appetite' and were 'unable to control their emotions'. 34 mothers (97.14%) were 'unable to sleep' and 22 mothers (62.85%) agreed that they were 'not able to concentrate'. Nineteen mothers (54.28%) were neutral on the items 'I get tired easily and I get irritated easily'. Ten mothers (28.57%) strongly disagreed that they 'get irritated easily'. All negative views in the order of priority of the weighted score was 1, 6 and 4. The first rank was given to the items 'I have no appetite' and 'I am not able to control my emotions'. The item least in the order was 'I get irritated easily'.

This table concludes that the mothers strongly agree that they have "no appetite and unable to control emotions" where as both fathers and mothers were unable to sleep well.

**TABLE – XI**  
**FREQUENCY AND PERCENTAGE DISTRIBUTION OF FATHERS AND MOTHERS**  
**WITH REGARD TO WORRY ABOUT THE CHILD CONDITION IN THREE POINT SCALE**

N=70

S.No	Items	Father (N = 35)						Weighted score	Mother (N = 35)						Weighted score
		SA		N		SD			SA		N		SD		
	Worry about	F	%	F	%	F	%		F	%	F	%	F	%	
A	Child growth	35	100	-	-	-	-	105	35	100	-	-	-	-	105
B	Child schooling	10	28.5	12	34.28	13	37.14	67	12	34.28	15	42.80	8	22.85	74
C	Survive like a normal child	34	97.14	1	2.85	-	-	104	35	100	-	-	-	-	105
D	Cost of the treatment	21	60.0	6	17.14	8	22.85	83	24	68.57	6	17.14	5	14.28	89
E	Child isolated from society	12	34.28	9	25.71	14	40.0	68	18	51.42	6	17.14	11	31.42	77
F	Physical changes	-	-	7	20.0	28	80.0	42	2	5.71	3	8.57	30	85.71	42

**Table-XI** presents frequency and percentage distribution of parents on three point scale with regard to worry about the child condition.

All the fathers (100%) strongly agreed that they were ‘worried about their child growth’. Thirty four fathers (97.14%) strongly agreed that their ‘child will survive normally’ and 21 fathers (60.00%) strongly agreed that they worried about ‘cost of the treatments’. Twelve fathers (34.5%) were neutral regarding their child schooling. Twenty eight fathers (80%) strongly disagreed that they worried about their ‘child bodily changes’ and 14 fathers (40.0%) strongly disagreed that their ‘child is isolated from the society’. Of all these negative views, worry about child’s condition in the order of priority of the weighted score was 1, 3 and 4. The first rank was given to the item “worry about child’s growth”. The items least in the order was ‘worry about child physical changes’.

All the mothers (100%) strongly agreed that they worried about ‘child’s growth’ and worried whether their ‘child will survive like a normal child’, 24 mothers (68.57%) strongly agreed that they worried about the ‘cost of treatment’. Fifteen mothers (42.80%) were neutral on the worry about the ‘child schooling’. Thirty mothers (85.71%) strongly disagreed that they worried about their ‘child’s physical changes’ and 11 mothers (31.42%) strongly disagreed that their ‘child was isolated from society’. All these negative views in the order of priority of weighted score were 1, 3 and 4. The first ranks were given to the items 1 and 3 that was “worry about child growth” and “survive like a normal child”.

This table concludes that the fathers and mothers strongly agreed that they worried about their child’s growth and if their child will survive like a normal child. These gave more stress to the parents when compared to others items.

**TABLE-XII**  
**FREQUENCY AND PERCENTAGE DISTRIBUTION OF FATHERS AND MOTHERS**  
**WITH REGARD TO FAMILY FUNCTIONING IN THREE POINT SCALE**

**N=70**

S. No	Family functioning	Father (N = 35)						Weig hted score	Mother (N =31 )						Weig hted score
		SA		N		SD			SA		N		SD		
		F	%	F	%	F	%		F	%	F	%	F	%	
a.	Do not get enough time to communicate with my spouse	8	22.85	3	8.57	24	68.57	54	6	17.14	3	8.57	26	74.28	50
b.	Unable to concentrate other children	9	25.71	9	25.71	10	28.50	55	8	22.85	15	14.28	15	42.85	49
c.	Not able to celebrate the festivals	13	37.14	11	31.42	11	31.42	72	22	62.85	6	20	6	17.14	86
d.	Unable to go out as I wish	24	68.57	6	17.14	5	14.28	89	13	37.14	3	8.57	19	54.28	64

**Table -XII** presents frequency and percentage distribution of parents on three point scales with regard to family functioning

Twenty four fathers (68.57%) strongly agreed that they were ‘unable to go out as they wished’ and 13 fathers (37.14%) strongly agreed that they were ‘not able to celebrate the festivals’. Eleven fathers (31.42%) were neutral the item related to the family functioning. Twenty four fathers (68.57%) strongly disagreed that they ‘do not get enough time to communicate with their spouse’, 11 fathers (31.42%) disagreed that they were ‘not able to celebrate the festivals’, 10 fathers (28.50%) strongly disagreed that and they were ‘unable to concentrate on the others children’. In all these negatives views, in the order of priority of weighted score was 4 and 3. The first rank was given to the item “unable to go out as I wish”. The item lest in the order was “do not get enough time to communicate with their spouse”.

Twenty two mothers (62.85%) strongly agreed that they were ‘not able to celebrate the festivals’ and 13 mothers (37.14%) said that they were ‘unable to go out as they wished’. Fifteen mothers (14.28%), were neutral in the item ‘unable to concentrate the festivals’. Twenty six mothers (74.28%) strongly disagreed that they ‘do not get enough time to communicate with their spouse’ and 19 mothers (54.28%) strongly disagreed that they were ‘unable to go out as they wished’. The first rank was given to the items “not able to celebrate the festivals” This item gives more stress to the mothers. The item giving least stress was “unable to concentrate other children”.

This table concludes that the mother had more stress as she was unable to celebrate the festivals and in fathers more stress was related to, unable to go out as wished.

**TABLE – XIII**

**MEAN STRESS SCORE AND STANDARD DEVIATION OF  
FATHERS AND MOTHERS IN THREE ASPECTS OF STRESS AND LEVEL  
OF SIGNIFICANCE**

**N=70**

<b>S. No</b>	<b>Aspects of stress</b>	<b>Maximum score</b>	<b>Father (N = 35)</b>			<b>Mother (N = 35)</b>			<b>Un paired t- test, value at p= &lt;0.05</b>
			<b>MS</b>	<b>SD</b>	<b>Mean %</b>	<b>MS</b>	<b>SD</b>	<b>Mean %</b>	
i.	Physical and psychological stress	25	19.62	4.2	78.48	23.4	2.6	93.60	4.8*
ii.	Worry about child condition	25	20.45	4.67	81.85	20.68	8.12	82.72	0.01 NS
iii.	Family functioning	25	10.17	4.36	40.68	10.54	2.25	42.16	0.056 NS

**\* Significant****NS- Non Significant****Table value = 1.67**

**Table – XIII** presents the mean score, standard deviation and level of significance of parents in three aspects of stress

Regarding worry about the child's condition fathers had high mean score of 81.85%, followed by physical and psychological stress (mean score 78.48%), with regard to stress in family functioning, the fathers obtained a low score of 40.68 %.

Mothers obtained the highest score of 93.6% in physical and psychological stress followed by worry about child's condition (mean score 82.72%), similar to fathers, mothers obtained the lowest score (46.16%) in family functioning.

Through the mean score shows a statistically high score among the mothers in all the three areas. Mothers experienced more stress than the fathers in physical and psychological stress.

Statistically there was no significant difference between the stress of the fathers and mothers with regard to worry about child conditions and family functioning.

However there was a significant difference in physical and psychological stress of fathers and mothers ( $t=4.8$ ,  $p<0.05$ ,  $df=68$ ).

**Figure – 7** highlights the fathers and mothers in three aspects of stress on leukemia.

**TABLE – XIV**

**MEAN STRESS SCORE AND STANDARD DEVIATION OF  
FATHERS AND MOTHERS IN OVER ALL STRESS AND LEVEL OF  
SIGNIFICANCE**

**N=70**

<b>S. No</b>	<b>Variables</b>	<b>Maximum score</b>	<b>Mean score</b>	<b>Standard Deviation</b>	<b>Mean Percentage</b>	<b>Un paired t- test, value at p= &lt;0.05</b>
1	Father (N = 35)	80	47.93	36.42	59.9	0.64 NS
2	Mother (N = 35)	80	53.96	41.80	67.45	

**\* Significant**

**NS- Non Significant**

**Table value = 1.67**

**Table- XIV** presents the mean score, standard deviation and level of significance of parents over all stress on leukemia.

Regarding the overall stress of parents on leukemia, the mean score obtained by fathers was 59.90% and mothers mean score was 67.45%. Though statistically mean score of the mothers was little high, no significant difference between the stress of the fathers and mothers with regard to leukemia (t- test-0.64, df-68, p<0.05). So the hypothesis (**H<sub>02</sub>**) was accepted.

This table concludes that both fathers and mothers have more or less equal stress on leukemia.

**Figure- 8** highlights mean score of fathers and mothers in overall stress on leukemia in percentage.



**TABLE – XV**

**FREQUENCY AND PERCENTAGE DISTRIBUTION OF PARENTS  
ACCORDING TO OVERALL STRESS IN THREE LEVELS ON LEUKEMIA**

**N=70**

S. No	DEMOGRAPHIC VARIABLES	LEVEL OF STRESS					
		MILD STRESS (0-26)		MODERATE STRESS (27-53)		SEVERE STRESS (54-83)	
		F	%	F	%	F	%
1	Father N= 35	-	-	24	68.57	11	31.42
2	Mother N=35	-	-	13	37.14	22	62.85

**Table-XV** presents the frequency and percentage distribution of parents on over all stress in three level of leukemia

Majority of (68.57%) of the fathers and 37.14% of the mothers had moderate stress on leukemia where as 62.85% of mothers and 31.42% of fathers had severe stress on leukemia.

From this table it was evident that, the stress was more in mothers, compared to fathers.

**Figure -9** highlights the frequency and percentage distribution of parents on over all stress on leukemia.

**SECTION – D ASSOCIATION OF DEMOGRAPHIC VARIABLES OF PARENTS AND CHILDREN WITH AWARENESS AND ANXIETY ON LEUKEMIA**

**TABLE-XVI**

**ASSOCIATION OF DEMOGRAPHIC VARIABLES OF MOTHERS WITH THEIR LEVEL OF AWARENESS ON LEUKEMIA**

**N=35**

<b>S NO</b>	<b>ITEMS</b>	<b>SOME WHAT</b>	<b>GREAT EXTENT</b>	<b><math>\chi^2</math> P= 0.05, df= 1</b>
<b>1</b>	<b>Age in years</b>			
	a. Less than 30	1	9	0.092 <b>NS</b> [3.84 (df-1)]
	b. more than 30	4	21	
<b>2</b>	<b>Education</b>			
	a. school	4	9	0.6 <b>NS</b> [5.99 (df-2)]
	b. college	1	7	

**\* Significance**

**Ns - non significant**

**Table-XVI** presents the association between demographic variables of mothers and awareness on leukemia.

There was no significant association noted among the level of awareness on leukemia and mothers age and level of education. Statistically proved that there was no significance ( $\chi^2$ -0.09 and 0.6).

**TABLE-XVII**  
**ASSOCIATION OF DEMOGRAPHIC VARIABLES OF FATHERS**  
**WITH THEIR LEVEL OF STRESS ON LEUKEMIA.**

**N=35**

<b>S NO</b>	<b>ITEMS</b>	<b>MODERATE STRESS</b>	<b>SEVERE STRESS</b>	<b><math>\chi^2</math> P= 0.05, df= 1</b>
1	<b>Age in years</b> a. 30-40 b. 40-50	15 9	6 5	0.005 NS [3.84 (df-1)]
2	<b>Education</b> a. school b. college	14 11	3 4	4.60* [3.84 (df-1)]
3	<b>Occupation</b> a. laborers b. business c. professional	9 9 6	3 6 2	0.31 NS [5.99 (df-2)]
4	<b>Income</b> a. up to 10,000 b.10,000-15,000 c. above 15,000	16 2 5	6 2 4	0.31 NS [5.99,(df-2)]

**\* Significance**

**NS - Non Significance**

**Table-XVII** - Association of demographic variables of fathers with their level of stress on leukemia.

There was a significant association between the educational status of the fathers with their level of stress. There was no significant association between the age in years, occupation and income of the family with their level of stress.

**TABLE-XVIII**

**ASSOCIATION OF DEMOGRAPHIC VARIABLES OF DATA ON  
CHILDREN WITH THEIR FATHERS LEVEL OF STRESS**

**N= 35**

<b>S NO</b>	<b>ITEMS</b>	<b>MODERATE STRESS</b>	<b>SEVERE STRESS</b>	<b><math>\chi^2</math> P= 0.05, df= 1</b>
<b>1</b>	<b>Number of child in the family</b> a. up to two children b. up to four children	19 5	7 4I	0.34 NS
<b>2</b>	<b>Age of the sick child</b> a. up to eight yeas b. above eight years	16 9	8 2	0.20 NS
<b>3</b>	<b>Birth order</b> a. First child b. Second child	17 7	6 5	0.30 NS
<b>4</b>	<b>Duration of illness</b> a. Less time one year b. more than one year	18 6	9 2	0.30 NS
<b>5</b>	<b>Durationof treatment</b> a. less than one year b. more than one year	18 6	9 2	0.30 NS

**\* Significance**

**NS- Non Significance**

**Table value = 3.84**

**Table - XVIII** presents association of demographic variables of data on children with their parent's level of stress.

There was no significant association between the data on children (Number of child in the family, Age of the sick child, Birth order, Duration of illness, Duration of treatment) and their parent stress level.

**TABLE-IXX**

**ASSOCIATION OF DEMOGRAPHIC VARIABLES OF MOTHERS  
WITH THEIR LEVEL OF STRESS ON LEUKEMIA.**

**N=35**

<b>S NO</b>	<b>ITEMS</b>	<b>MODERATE STRESS</b>	<b>SEVERE STRESS</b>	<b><math>\chi^2</math> P= 0.05, df= 1</b>
1	<b>Age in years</b> a. 20 - 30 b. 30-40	6 5	6 18	0.05 NS
2	<b>Education</b> a. Illiterate b. school c. college	4 4 5	10 9 3	4.60*

**\* Significance**

**NS- Non Significance**

**Table value=3.84**

**Table-IXX** presents the association between mothers and level of awareness.

There was a significant association between the demographic variables of mothers education with their level of stress.

There was no significant difference between the demographic variables of mothers age with their level of stress.

**TABLE-XX**

**ASSOCIATION OF DEMOGRAPHIC VARIABLES OF DATA ON  
CHILDREN WITH THEIR MOTHERS LEVEL OF STRESS**

**N=35**

<b>S NO</b>	<b>ITEMS</b>	<b>MODERATE STRESS</b>	<b>SEVERE STRESS</b>	<b><math>\chi^2</math> P= 0.05, df= 1</b>
<b>1</b>	<b>Number of child</b> a. Up to two children b. up to four children	10 3	16 6	0.03 NS [3.84 ,df -1]
<b>2</b>	<b>Age of the sick child</b> a. up to eight yeas b. above eight years	9 3	14 9	0.21 NS [3.84 ,df -1]
	<b>Birth order</b> a. First child b. Second child	11 2	12 10	2.13 NS [3.84 ,df -1]
<b>4</b>	<b>Duration of illness</b> a. Less time one year b. more than one year	12 4	15 4	0.30 NS [3.84 ,df -1]
<b>5</b>	<b>Duration of treatment</b> a. less than one year b. more than one year	9 4	18 4	1.46 NS [3.84 ,df -1]

**\* Significance**

**Ns- non significance**

**Table value = 3.84**

**Table - XX** Present association of demographic variables of data on children with their mothers level of stress.

There was no significant association between the data on children (number of children, age of the sick child, child birth order, duration of illness and duration of treatment) and their mothers stress level.



# **DISCUSSION**

## CHAPTER – V

### DISCUSSION

The study focused on assessing the parents awareness on leukemia and their level of stress as the child undergoing leukemic treatment in a selected hospital. This chapter presents the findings and its discussions.

**Table - I** presents the demographic characteristics of the sample. The samples included in the study were between the age group 20-50 years. Among them, the fathers 37.1% were laborers, 25.70% were business men and remaining agriculturist, professionals and worked in other areas.

The present study finding is supported by a study done by **Coft J.S. Blair**, on parental occupation exposures and risk of childhood cancer. A relationship between parent exposures to chemicals leads to childhood leukemia. In this study, children of 37.1% fathers (laborers) got leukemia.

**Table - IV** presents the frequency and percentage distribution of parents according to overall awareness on leukemia. Majority (91%) of the fathers and (89%) of the mothers had a high level of awareness regarding leukemia.

**Tushti Bhardwaj (2008)** conducted a study on level of awareness about cancer among college youth. This study emphasizes the need of strong knowledge base about cancer, there is an urgent need of countrywide information and education and communication campaign about cancer so that general population can easily identify initial symptoms of the disease. In this study the results clearly shows that the parents had more awareness about leukemia.

**Table – V** presents the mean awareness score of parents with regards to meaning of cancers, reason and manifestation of leukemia. Majority (92%) of the fathers and mothers (94.84%) had awareness on signs and symptoms of leukemia. Lowest score obtained by fathers (46.2%) and mothers (37.6%) on meaning of cancer.

An epidemiological study (1998) concluded that the evidence for an association between childhood leukemia and paternal exposure to solvents is “quite strong”. In this study there was a significant difference between the fathers and mothers awareness with regard to reason for leukemia.

**Table – VI** presents the mean awareness score and level of significance of parents in diagnosis, treatment, blood transfusion, advantage of treatment and care of the child with leukemia. The mean awareness score obtained by fathers were 97.14% in advantage of the treatment on leukemia and mothers were 94.8% in the area of diagnosis of leukemia. There was no significant difference between parents among all the areas of awareness. This study showed that the parents had adequate awareness about the advantages of the treatment.

**Table – VII** presents the mean awareness score and level of significance of parent’s awareness on leukemia in various aspects. Highest (90.80%) mean score of the fathers and mothers (92.5%) obtained from care of the child. There was significant difference between the parents on meaning and reasoning of leukemia. There was no significant difference between the parents and diagnosis, treatment and care of the child with leukemia.

A similar study conducted by **Cubukcu CE et al, (2008)** regarding the parental perceptions of the importance of dental care and preference with regards to its provision while profiling the level of dental health knowledge among the parents of leukemic children were elicited. In this study, the results showed that the parents had adequate awareness about care of the child and also in providing effective care.

**Table – VIII** shows the mean score, and level of significance of parents overall awareness on leukemia. The overall level of awareness of fathers on leukemia was 48.27% and the mothers were 46.48%. There was no significant difference between the level of awareness of parents on leukemia.

A study conducted by **Mostert S et al, (2009)** compared about childhood leukemia treatment outcome before and after introduction of parental education program. The results show that after introduction of education program, treatment refusal decreased (14% - 2%) and event free survival increased (13%-29%) significantly in poor patients. Treatment abandonment increased (0%-13%) significantly in prosperous patients. The parents had awareness on leukemia. The results showed with education the awareness was improved and there was decrease to refuse the treatment, but in this study without education the parents had adequate awareness about the leukemia.

**Table - IX** presents the frequency and percentage distribution of parents according to level of stress in three areas. Forty percentage of the fathers, 86% of the mothers had severe stress on Physical and psychological, 57.0% of fathers and 77% of the mothers had severe stress on worry about the child's condition. Sixty nine percentages of the fathers and 85% of mothers had moderate stress on family conditions.

**Streisand R (2001)** conducted a study to assess the parental distress during pediatric leukemia and posttraumatic stress symptoms (PTSS) after treatment ends. Highly anxious parents are at risk for PTSS and may benefit from approaches that decrease anxiety during treatment and afterward. This study concludes that the mothers had more severe stress in physical and psychological stress and worry about the child condition, when compared to fathers.

**Table - XI** frequency and percentage distribution of fathers and mothers on three point scale with regard to worry about the child condition. The fathers and mothers were worry about child condition the highest (105) weighted score was item (1) ‘worry about child growth’, followed by 104 weighted score in item (3) ‘worry about whether their child survive like a normal child’.

**Rohrer R L (1995-2005)** conducted study to explore unique role of parental visitors of children with cancer. Using oral interviews with parents, medical and psychosocial staff, and the study explores the experiences of parents (social, emotional, financial and family issues) while in hospital with their children during admissions. The results shows that the fathers and mothers strongly agreed that worry about the ‘child growth and survive like a normal child’ giving more stress to the parents when compared to others items.

**Table - XIII** mean stress score of fathers and mothers in three aspects of stress and level of significance. Regarding ‘worry about the child’s condition’ fathers had high mean score of 81.85%, in mothers 82.72%, the fathers obtained mean score of 78.48% and 93.6% in mothers regarding physical and psychological stress. On family functioning the fathers obtained a low score of 40.68%, and in mothers 46.16%.

A study done by **Bennett Murphy LM (2008)** examined the role of fathers caring for children with cancer. Psychological adjustment, coping, and work patterns of mothers and fathers were described. Twenty fathers of children with cancer were compared with 20 mothers of children with cancer and 20 control fathers of healthy children. The results showed that fathers did not differ from mothers or control fathers in terms of psychological adjustment or coping. However, fathers of children with cancer spent more hours at work and more hours caring for children’s than did control fathers. In this study the results showed that the parents are worry about their child’s condition.

**SUMMARY,  
FINDINGS,  
CONCLUSION,  
IMPLICATION AND  
RECOMMENDATION**

## **CHAPTER VI**

### **SUMMARY, CONCLUSION, IMPLICATION AND RECOMMENDATION**

This chapter discuss about the summary of the study, findings, conclusion, implication and recommendation.

#### **SUMMARY OF THE STUDY**

The study was conducted to assess awareness on leukemia and their level of stress with regards to leukemia (Physical and psychological, worry about child condition, family functioning) a descriptive survey approach was used. The study was done on 35 fathers and 35 mothers selected by a convenient sampling technique from a selected hospital at Coimbatore. The data was collected through interview method by using questionnaire, the parents stress was assessed by stress scale. The data was analyzed by using descriptive and inferential statistics.

#### **SUMMARY AND FINDINGS**

##### **Demographic Data**

The age of parents ranged from 20-50 years, most of the parents both fathers and mothers 62.85% were in the age group between 30 - 40 years. Regarding educational status, 42.85% of the fathers and 22.85 % of mothers were graduates. All fathers and five mothers were working where as remaining are housewives. Most of the fathers were from income group of below 5000/-. Most of the children were first child (65.71%). The duration of illness is 60% less than six month, whereas duration of treatment less than six months is 74.29%.

### **Awareness on Leukemia**

Thirty two fathers (91.0%) and 31 mothers (89.0 %) had a high level of awareness regarding leukemia. Only three fathers (9.0 %) and 4 mothers (11.0%) showed a moderate level of awareness with regard to leukemia.

### **Overall Stress**

Majority (68.57%) of the fathers and 37.14% of the mothers had moderate stress on leukemia where as 62.85% of mothers and 31.42% of fathers had severe stress on leukemia.

### **Significant Findings**

Regarding the overall awareness on leukemia, the mean score for fathers was 80.45%, and for mothers it was 77.46%. Though the mean score of the fathers was higher than mothers, no significant difference was noted between the awareness of fathers and mothers with regard to leukemia (t- test-1.21, df-68,  $p < 0.05$ ). So according to hypothesis (**H<sub>01</sub>**) there was no significant difference between the awareness of fathers and mothers having leukemic child.

Regarding the overall stress of parents on leukemia, the mean score obtained by fathers was 59.90%, and mothers mean score was 67.45%. Though statistical values are high for mothers, there is no significant difference between the stress of the fathers and mothers with regard to leukemia (t- test-0.64, df-68,  $p < 0.05$ ). So the hypothesis (**H<sub>02</sub>**) was accepted.

There was an association between the demographic characteristics of fathers educational status with level of stress on leukemia. ( $X^2 - 4.6$ , df – 1,  $p - 0.05$ ).



## **CONCLUSION**

The study concludes that most of the parents (Fathers and Mothers) had equal awareness on leukemia, but they had severe stress with a leukemic child undergoing treatment.

## **IMPLICATION**

The study has its implication in Nursing practice, Nursing education, Nursing Administration, Nursing Research and Community.

## **NURSING PRACTICE**

Nurses are the majority in health care setting. The finding of the study clearly highlights the problems experienced by the parents. The health care providers of hospital provide awareness programme regarding leukemia.

The nurses can develop skill to explain care during the illness, counsel the parents to adopt the situation. Nurse can teach about personal hygiene and its importance, to protect the child from infection.

Nurse can educate the parents about their stress management like exercise, games, walking, changing the environment and divisional therapy.

## **NURSING EDUCATION**

Before nurses can utilize their practice, they need to have strong foundations in terms of education. Nurse's educators not only have a role for the students but also newly appointed staff. The education in the clinical areas could be in the form of,

- ❖ to create awareness regarding leukemia
- ❖ updating the knowledge of the staff by proper and relevant in-service education programs to related to leukemia.
- ❖ conduct the ward teaching, staff development programme.
- ❖ nursing rounds for both students and staff in the hospital and community
- ❖ the nurse educators take responsibility or should provide more opportunity to conduct survey and community screening.
- ❖ she should teach about early detection of leukemia to create public awareness.

## **NURSE ADMINISTRATOR**

Nurse administrator should be efficient in organization of programme regarding awareness on leukemia.

A special nurse practitioner can be appointed in the outpatient department to provide counseling to the parents and family members to overcome the stress and anxiety and other related psychological problems.

Nurse administrator must plan and organize education Programme regarding awareness on leukemia and its treatment modalities for the nursing personnel and other health team members to update their knowledge.

## **COMMUNITY**

Community nurse has an important role to identification, early detection and prevention of illness. During home visit, the nurse can create awareness on leukemia.

## **NURSING RESEARCH**

There is a need for exclusive research in this area. A research can be done to assess the parents awareness on leukemia and their stress level in community settings.

### **RECOMMENDATION:**

- The study can be replicated for large sample for generalization
- Maximum publicity should be given through mass media for creating awareness among public about the reason and its treatment available in the health care system
- A similar study can be conducted, to assess the coping level of parents to overcome the stress level.
- A similar type of comparative study can be done between hospital and community settings.
- This study can be replicated in various settings.

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